Mad in America
SCIENCE, PSYCHIATRY AND SOCIAL JUSTICE

Editor's Note: This interview of Anniek Lemmens by Mad in the Netherlands' Monique Timmermans first appeared on Mad in the Netherlands on February 24, 2024.

I'm happy to see Anniek, 40 years old, again. She looks more fragile than she did last spring, and I can see that she is suffering. When I hug her, I can feel our nervous systems connect with a sigh of relief. She could have been me, and I could have been her. Four years ago, we were similarly facing the horrors that come from antipsychotic withdrawal after tapering from medication too quickly, and in Anniek's case, from an antidepressant as well. Today, as editor of Mad in the Netherlands, free from medication, still suffering from persisting withdrawal symptoms, but also enjoying a quality of life, I am visiting one of my withdrawal buddies to write down her story before she, because of the persistent suffering, will die by euthanasia. Not because she has chosen to die, but because she can't continue to live the life as it became.

That story is how improper psychiatric guidance, particularly inadequate guidance on medication titration, can cause immense pain and suffering for patients. There is certainly some accountability towards the prescribers, but her story is mainly of reconciliation and a call to work together. True, the consequences are more drastic for Anniek and her loved ones with her soon-to-be death than for the prescribers who will have to come to terms with the idea that they were not correctly informed, and thus too often provided patients with incorrect information and did not treat them with enough care. But it may be said that all are part of and trapped in the same suffocating system. We will remain trapped until, together, we dare to decide to do things differently. I write this for Anniek and all victims of prescribed psychotropic drugs and their loved ones.

Monique Timmermans: I have only known you in the context of withdrawal, having met you after your tapering from medication went wrong. What was your life like before?

Anniek Lemmens: By nature, I am adventurous. I have always sought out a wide range of activities despite the difficulties I encountered in my life. I like social interaction, variety and a bit of commotion. In 2009-2010, I had a very tough time. It was then that I was put on quetiapine (Seroquel) and citalopram (Cipramil) after trying various psychiatric drugs. But afterwards, I picked up my life. I really miss my life prior to tapering and especially all the different aspects of my life. I enjoyed being an aunt, I loved studying and working, hanging out with friends, running outside, making music with others and taking long walks with the dogs I used to babysit. I loved to cook and bake and I loved to take pictures….

We made a collage from memories of those days. It is displayed in the room. At first I found it hard to look at it. It's so confronting to see the life I could have had…

I still occasionally take pictures. All the other stuff, even little things that made my life worth living, I am no longer able to do. I used to really enjoy doing the dishes with my husband. Now I lie on my recliner with noise cancelling headphones, while he cleans up the kitchen.

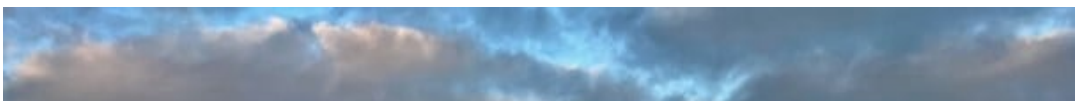

Photo by Anniek Lemmens: Infinity

Monique: That is a huge contrast indeed with the Anniek I know. Would you tell us a little bit about what it was like for you in the mental health system before you went into withdrawal?

Anniek: I was first admitted as a 16-year-old, being prescribed paroxetine (Seroxat) and fluoxetine (Prozac). That didn't improve how I felt at all. For example, about fluoxetine, it has recently been established that it is the placebo effect and not the drug itself that is responsible for adolescents recovering from depression. Paroxetine may no longer be prescribed to adolescents because the drug can trigger suicide. Quite rightly so, because these drugs made me do things I would never choose to do myself. For example, I walked across a busy intersection with my eyes closed. Being admitted to that institution didn't do me also any good, because they did not (could not?) offer any therapy besides prescribing psychotropic drugs. My father was seriously ill at the time; he was dying and the relationship I had with my mother was very difficult back then. In that condition, I attempted suicide. In retrospect, the pills drove me to it rather than saved me from it. Isn't it strange that we pay so much attention to what liquor does to the developing adolescent brain, while the prescription of such medication is hardly ever questioned.

After admission in psychiatry, I went to live with a foster family. When my father died six months later, I quit the medication pretty quickly and after a week of withdrawal, I was okay.

In 2009-2010, things did not go well for me due to a combination of extreme

insomnia, a seriously diminished self-image, setbacks in all kinds of areas and the partial loss of my social safety net. As a result, I ended up in a crisis unit where the goal was to "set me up on medication". Given the condition and circumstances I was in at the time, I felt I had very very limited freedom of choice in what I was prescribed. Various drugs were tried during that period, which I initially got off fairly easily. It was also then that I started taking quetiapine (Seroquel) in addition to citalopram for a better night's sleep. At that time, the use of benzodiazepines for that purpose had become discredited (because of the risk of addiction). Therefore, doctors at that time began to increasingly prescribe off-label quetiapine (an antipsychotic that can combat agitation) for sleeping problems. What I regret is that I didn't realize the serious impact of such a drug; moreover, within 3 days, I was on 200 mg. Even though I was sleeping very well from day 1 when I was only taking 50mg, according to my file, the dose was increased as planned. With hindsight, now that we know how difficult it is to taper these drugs, giving me the extra 150mg that wasn't even necessary, was quite cruel. Especially when you consider that it is now known that women react differently to antipsychotics than men (de Boer, Brand, Sommer 2022).

Nevertheless, I want to make it clear that I am in no way negative toward psychiatric counseling. I embraced mental health support for many years because I found that it made me healthier. I did mindfulness, CBT (Cognitive Behavioral Therapy), PMT (Psychomotor Therapy), exposure, EMDR (Eye Movement Desensitization and Reprocessing), ACT (Acceptance and Commitment therapy), systems therapy, exercise and lifestyle therapy, graded activity and peer support, including WRAP (Wellness Recovery Action Plan). Thanks to a variety of therapies and social factors, I had managed to develop a positive self-image and resilience that made life truly worth living again. Over the years, the diagnoses all fell away. Almost all of the disorders that I had been diagnosed with were in complete remission. But I was still stuck on the medication (quetiapine, citalopram) because each attempt at tapering off triggered severe withdrawal symptoms and physical discomfort, despite my healthy lifestyle. I was able to trace those discomforts as side effects of the drugs as listed on the package inserts. When I did manage to taper off a bit, I felt an immediate improvement in my health. Therefore, in 2019, I decided to get start tapering once again. I did everything I could to make conditions as optimal

as possible, so that I would succeed this time.

Monique: So how did you approach tapering off?

Anniek: I had cleared six months of time to make sure I had time for optimal self-care. The reason why I wanted to reduce was clear. I had also created a WRAP plan, found people to support me and created a crisis card for psychological crisis due to withdrawal symptoms. I was super-motivated to go on withdrawal. I knew it would be no fun. That's why I also asked my psychiatrist not to be 'too soft' with me and help me push through when things got tough. In hindsight, I really regret that….

Monique: So you said they shouldn't be "too soft" with you during the withdrawal?

Anniek: Yes indeed! I tapered off citalopram with tapering strips between October 2019 and January 2020. Using self-monitoring forms, I documented my symptoms. I suffered from sadness, fatigue, pain, poor sleep and an urge to overeat. I noticed that my body had to work hard to stay balanced. I didn't find that strange after 10 years of using medication. It did help that I took time off work during the tapering period. That made my progress relatively good. My psychiatrist never enquired after my self-monitoring forms. Therefore, he thought I had no withdrawal symptoms or recurrence of anxiety or mood symptoms. Unfortunately, this was not the case. Now that I know how important it is to take those symptoms seriously, perhaps I should have informed the psychiatrist more emphatically about the symptoms I was experiencing at the time, even though he never asked about this. Maybe then, we could have opted for a slower withdrawal schedule. Most probably, because I always pretended I was strong and did not complain too much, a number of signals were missed by him and therefore he did not sufficiently investigate them. However, I don't know whether it would have made any difference. Because when I was tapered off the quetiapine between February and April (also with tapering medication) I did tell him that things were not going well, but he did not respond adequately.

I suffered from fatigue, poor sleep, nightmares, headaches, lethargy, sadness and crying during the first month. Tapering off the antipsychotic was harder for

me than withdrawing from the antidepressant. In the second month I started to suffer from muscle pain, back pain and extreme fatigue in addition to the symptoms that I already had. In the third month, I started to feel increasingly overstimulated, cramped, dizzy, I had trouble concentrating. I could no longer focus my eyes and hardly slept at all, making me increasingly unstable. Events that I could normally handle just fine were suddenly too much for me because of the severe withdrawal symptoms. I requested crisis admission at one point because I was too sick to stand, sit, eat or drink. It was a cry for help that went unheard. My psychiatrist said an admission wasn't going to happen and that I just needed to push through it.

I pulled myself together one more time, ignoring all the alarm signals that my body was giving of. A calendar from which I tore off a leaf every day, kept me going; I assumed that after 60 terrible, long days my quality of life would improve, and that sustained me. I took my psychiatrist's 'professional knowledge ' more seriously than what I felt in my own body. While the psychiatrist focused on my mental instability, he completely ignored the thing that was draining my resilience, making me less and less able to cope—namely the withdrawal from drugs. For instance, according to my psychiatrist, I was unstable because of my cat being sick. But I was so disrupted by the withdrawal symptoms that I could not cope with visiting the vet and I became terribly overwrought. I couldn't offer my cat what it needed, and this was terrible to me. I tried to make that clear, but he didn't listen.

That "not too soft" approach to withdrawal has been the crux. The self-monitoring forms serve to allow the practitioner to see if new symptoms appear during tapering or if existing symptoms get worse. As soon as this happens, it is best to reduce the amount with the dosage is reduced (with mutual consent), to taper more slowly, stabilize at the same dose to wait and see if the symptoms diminish or disappear. One can also decide to return to the last dosage at which things were going well, or decide not to reduce the dosage any further. The one thing that should never be done is to continue tapering, when the symptoms get worse. A doctor should not fall into the trap of thinking 'I am dealing with a psychologically unstable person, so that is the cause of the symptoms and not the withdrawal'.

The purpose of made-to-measure tapering medication is precisely to offer the possibility of phasing out more slowly, because it is known that tapering becomes more difficult at the lower doses. The chances of tapering successfully increase if smaller doses are tapered off over a longer period of time. For a long time, I felt guilty; perhaps, by saying that I did not want to be treated like a softie, I myself may have been the cause of now being unable to recover.

Monique: Aren't you being too hard on yourself? Surely you can assume that a psychiatrist who knows how to prescribe pills also knows how to get off them safely? You were given the quetiapine off-label, i.e., not for psychosis but for sleeping. They weren't prescribed to you for the rest of your life, are they? In my opinion, that's why prescriptions for such a drug should never be long repeated. Especially if prescribers don't know how to taper these drugs safely and in a timely manner with their patients.

Anniek: I wouldn't put it that strongly. Of course, not everyone has such extreme symptoms as I have now. Because I planned everything to make it the circumstances as good as possible, I set the bar too high. I was willing to go deep to get through withdrawal. My psychiatrist had explained to me that withdrawal symptoms only lasted for a short time. Therefore, I kept thinking, "just for a little while." So in retrospect, that was the stupidest thing to do. Those withdrawal symptoms were actually relevant. I do retroactively blame my psychiatrist for hiding behind guidelines based on old "science" and pretending that withdrawal was not that bad. As a prescriber, when my symptoms became so severe, he should have started thinking beyond the guidelines and actively seek out information, which was already out there at the time. Full reliance on a guideline may cause prescribers not to take situations that take a turn for the worse seriously. This has certainly been the case with me.

My psychiatrist seemed primarily focused on psychological symptoms that might reappear when the medication was phased out because those symptoms had previously been suppressed. The fact that I did not become suicidal or develop a psychosis were considered more important markers than the physical symptoms that I described to him. But you know, I have never suffered from psychosis in my life; I was prescribed the medication to be able to sleep. So it is

not surprising that I did not relapse into psychosis. The symptoms that I did suffer from were considered annoying but insignificant. They were filed under the somatic complaints that I previously gave as a reason for tapering off. But actually, these things did not compare at all. The (physical) withdrawal symptoms were really incredible. The fact that I persevered says more about my willpower than about the ferocity of the symptoms. So I really want to emphasize the importance of taking such indications very seriously. If you respond in time, there is a good chance that a small adjustment in your discontinuation schedule can help you become stable again. This is a joint responsibility of the prescriber, the person tapering off and their loved ones. It is very important that all parties get involved. However, as a professional, the prescriber does have a leading role here.

Monique: Under every blog, article, and video that deals with tapering and withdrawal, it is advised that you should never taper without consulting your treating physician. Given the severity of your withdrawal symptoms, and also my own, I can only agree. Of course, it is of the utmost importance that that prescribers inform themselves about what recent information is available and that they do not blindly rely on guidelines, especially those parts of the guidelines where they do not incorporate the latest scientific developments and insights. The Stichting Pill meticulously substantiated this in their response to the 2023 Multidisciplinary Document "Phasing Out Other Antidepressants. For example, the websites theinnercompass.org and survivingantidepressants.org contain a wealth of experiential knowledge. On the Mad in The Netherlands website we have an excellent information video from IIPDW on safe withdrawal and withdrawal symptoms by clinical researcher and experiencer, Dr. Mark Horowitz. The Vereniging Afbouwmedicatie has prepared a document that lists various options for obtaining customized medication.

During withdrawal, you battled through your withdrawal symptoms purely on willpower, because your psychiatrist told you they would only be short-lived. Was that assumption correct?

Anniek: After the last pill, I received a card from my mother-in-law. She congratulated me and wished me strength with this "new phase" which does say something about how I felt at that moment. When I was completely off the

medication, I was completely, deeply exhausted. In my mind, the word "castaway" pops up regularly, involuntarily. But I was still able to meet up with people for parts of the day, do a little bit of housekeeping, drive short distances, or go biking, walking for a bit. There were no symptoms of severe auditory and visual overstimulation yet, there were no crying fits. The problem was mainly the constant worsening of the chronic fatigue that I had been suffering from since when I started with the medication.

Between April 2020 (last pill) and August (4 months later), I was not that worried yet. I felt that my remaining withdrawal symptoms would recover. Not much was required of me yet, I had no obligations, which meant I could still do a few things, such as volunteer to teach a withdrawal course at Enik Recovery College. In the meantime, however, I was starting to change my opinion about the content of the self-help course I was teaching. I didn't want to tell the participants what to do, but I felt an increasing need to warn them about tapering off.

On August 8, 2020, I first noticed that something was going wrong in my head. Together with my husband and his parents, we went to visit my brother-in-law. In the car on the way there I was already, in a way unknown to me until then, exhausted. I could no longer follow the conversation, I could not focus and I lacked concentration. The muscles in my face and head were so cramped that my face was frozen; I could no longer make facial expressions. I lay down on the bed to rest; normally I would snap out of it after a bit. I lay down for an hour, but it didn't change I still have that weird feeling in my head. Normally, it would go away after a bit, but this time, it didn't work. From then on, I deteriorated very rapidly.

On the 9th, I started my rehabilitation program at Winnock. The course of graded activity really appealed to me, it gave much more support than what I had experienced with psychosomatics in the mental health system. But soon every activity, no matter how short, became too much. The first week I cycled 4 km on my regular bike. The second week I had to take the electric bike and barely managed to cycle 4 km; before tapering, I could easily cycle 50-100 km per week on a regular bike. By the end of the second week, I could no longer participate in the group. I could no longer sit. I could only lie down and cry. Not from sadness; I didn't understand what was happening to me. I cried from exhaustion.

Monique: What you say is so recognizable. I myself expected to feel much better after 6 weeks of "detox," but the opposite was true. I became sicker than ever. After 7 months, I started a rehab program at CIR rehab. Part of it included exercises. But instead of building up strength, things got worse every day; I could do fewer and fewer exercises, I could do them less often, and I could do them for a shorter period of time. It was a negative spiral. Fortunately, we then decided by mutual agreement that, apparently, it was too soon for training and instead focused on mindfulness, discovering what energizes me and saps my energy, practicing body awareness and gentleness. I had a very nice psychologist who understood my anger, which made room for grieving. We often walked outside, gently strolling through the park. That was okay. And they also taught me to take charge of my own self, to understand my body's signals and respond to them regardless of what others think.

I think, besides continuing to taper despite your body indicating that it was becoming too much, this was another one of those crucial, make or break moments. Is that right?

Anniek: Yes. I went on vacation with my husband to a Wadden Island for a few days in September that year. Cycling was no longer possible. I still managed to walk a bit, I was able to sit in the bus and we went out to dinner together. We made the best of it. On the train on the way home, the blow came. Then again came that immense exhaustion that made thinking and doing impossible.

From then on, I deteriorated like crazy, and the struggle to get appropriate care also began. I became so ill that sitting, standing, eating and drinking were no longer possible. A 15-minute conversation was already too much. In a few months, I lost about 8 pounds. Except for giving me drinking formula, practically nothing happened in terms of help. My fear and anxiety increased because of the extreme intensity of my illness, which was not sufficiently recognized. I did not understand what was happening to me. I had never experienced anything so intense and I felt that I was actually becoming damaged and was overwhelmed by gigantic exhaustion and a lot of pain. To my dismay and sadness, I was also stigmatized and abandoned by health care providers. Whether this was because of the guideline that predicted that I could not have serious long-term symptoms after weaning myself off the drug, or whether it was because of my past, which

automatically assumed that it would be “psychological,” I cannot say.

I believe August and September were critical months. If I had been advised then to restart medication as soon as possible, I might have been able to stop the deterioration in time. Being as sick as I was from September through January is indescribable. I don’t think I would have survived if I hadn’t eventually restarted medication.

Monique: I hear what you are saying. Oddly enough, I have just the opposite feeling, that I would not have survived with pills. By then, I had read reports from other people with akathisia that, when you restart from a dysregulated central nervous system, after a longer time without medication (i.e., more than a month), the outcomes are different. Thus, for me it was unthinkable to restart. My body reacted so extremely to every little substance that I was afraid to add anything else when I could not predict the outcome. Yet, I know someone who hardly experienced any withdrawal problems after restarting with quetiapine after not taking the medication for almost 2 years. I also know you, whose withdrawal plateaued; it neither improved nor worsened. For myself, I now know that I am improving without restarting medication.

When I say it like this, I feel guilty given your circumstances. I know how terribly I too have suffered and how much it has taken from me to reach where I am now, but it feels unfair; you have worked just as hard….

There is clearly no “one-size-fits-all” answer to the extreme withdrawal we experienced from tapering too quickly. In your case, you say that you would have been out of it without medication. So then, restarting was your only chance?

Anniek: Unfortunately, it took longer than was good for me to restart. I tried to sort it out from the beginning of October 2020 by first approaching my last psychiatrist. However, he discouraged me from restarting as did a colleague from the pharmacogenetics department. In November, I inquired with a pharmacist who also advised me against starting again. Then I visited an empathetic internist who referred me to a neurologist who advised me (less empathetic) to try psychosomatic physical therapy (of which it had recently been

proven that my body did not react well). Because this neurologist also thought that I should take responsibility myself if I wanted to get better and I lost hope for appropriate help, I started taking quetiapine again out of sheer desperation at the end of December 2020. My family doctor had previously suggested that as an option. I had, because I was getting opposite messages and it felt like a "loss" to start again, not taken that up until then. Finally, I took the gamble to start again. The drug began to do its job after four weeks. Although deterioration was halted from then on, unfortunately real progress was also lacking. In the meantime, I still had no support for my persistent withdrawal symptoms and I lacked a physician who was actively thinking about which investigations or solutions were possible at that time. I really felt abandoned to my fate.

Monique: How lonely you must have felt… I remember how I had a similar feeling. Nobody knew a solution so quickly, so I had to come up with one myself. I just had no idea where and what to look for. Actually, that feeling back then, that lonely hopeless search while I was deathly ill, was the basis for Mad in the Netherlands (making information findable).

You mentioned that your deterioration was halted from the restart with medication, but did not improve. What has your clinical picture been like since then?

Anniek: I am always in pain. My body reacts so extremely violently to sound that it feels like I'm being tortured. It is an assault on my body when, for example, the central heating boiler turns on. I get nauseous, have to gag, collapse and cry for no reason. I'm so tired because of this and I keep getting worse. The worst part is that I can no longer be with or without people. As soon as some sounds mix (kettle, bleep of phone), I get completely overstimulated. For this reason, a relaxed conversation with friends or family is no longer possible. As a result, I can no longer see the cousins I love so much. I can't go to the village for an errand, to eat ice cream or just to go for a walk. This overstimulation to sound is always there; there are no good days. Every day I have to withdraw myself about 4 to 8 times in a dark room with soundproofing. Actually, almost everything that made my life fun (music, running, walking with the babysitting dogs, conversations with friends, work) has become impossible. I no longer recognize myself as the disabled woman I have become.

There is actually over-stimulation and under-stimulation at the same time. If I do something I don't succeed because of the overstimulation. If I do nothing I become unhappy because of the under-stimulation. I get bored, lack variety and feel isolated from everything and everyone. We even investigated whether making myself voluntarily deaf is a solution. We were always advised against that because the overstimulation is not from the ears but from the brain. I would have liked to try it, but the thought that it would get worse that does not attract me.

Monique: So, was there nothing that helped?

Anniek: Well, something. Because of a comment in a Facebook group for "people with non-congenital brain injury (NAH) and overstimulation," I admitted myself to the crisis ward in February 2021 to have an NPO (neuropsychological examination) taken. I was hoping to be taken more seriously when it was proven that my symptoms were not psychological. An outpatient neuropsychologist, who did not stigmatize me, made sure I received support from professionals in NAH. Indeed, as I myself always pointed out, no indications of underlying psychological problems were identified. On this, counseling by professionals in NAH actually started in July 2021. Their help was gold. Unfortunately, that stopped when we moved to the far north in April 2022, hoping that the quiet there would give me a real chance for recovery. The next specialist I visited after that again did not believe I had drug damage….

Monique: How frustrating that must have been, going through so many specialists, having to prove over and over again that your symptoms are not psychological, and fighting for recognition of your problem—it is asking for misery, isn't it?

When you made your very first intake within the mental health system because you were struggling with psychological problems, no doubt everything you said was taken incredibly seriously. But then, after years of effective therapeutic treatment in which you have shown tremendous personal growth, every complaint you mention due to withdrawal is no longer taken seriously—or it is blamed on a "return" to your original disorder. It is strange to have lost your credibility despite your tremendous personal growth…

I can also turn it around. When I myself came to the psychiatrist for disturbed grief, which I thought was a mental problem myself, I was given a chemical solution, as there was a supposed substance missing for which I would need lifelong medication, according to my psychiatrist. But when I tapered off that chemical, my withdrawal symptoms were suddenly psychological.

I am pretty sure for myself that there is traumatic chemical brain injury (TCBI). Actually, there is a corresponding finding to that of your neuropsychological examination. In the withdrawal groups, they often use terms like "PAWS," Post-Acute Withdrawal Syndrome, or "PWS," Protracted (or Prolonged) Withdrawal Syndrome.

Would it have made any difference to you if you hadn't had to fight so hard to find help for your symptoms?

Anniek: Yes indeed… People regularly talk about my euthanasia wish. But it's not a wish. It's an alternative to me doing it myself one unbearable day because, in the end, I can't sustain this. Since I know I am going to die, I was more concerned with how to end my life properly than with wishing that I want my old life back. Recently when a spiritual caregiver asked how it came to be this way, I did feel that it would have made a huge difference if doctors had believed me and convincingly done their best for me. Now I wasted so much energy trying to convince them.

That is why I think it is very important to let people know that discontinuation complaints, as well as the patient, should be taken seriously.

It was never my intention to fight with my prescribers. In an ordinary conversation they didn't seem to want to hear me. They kept going back to their guidelines with outdated information where there was hardly any room for understanding or compassion. But when a patient sits across from you and tells you how much discomfort she is experiencing, one might assume that she is not just saying that for fun. That such a specialist will then look for the reason why the symptoms deviate from the guideline and what can possibly be done about it? But because they always looked back in the file first, they could no longer look at it objectively. They kept attributing my symptoms to a non-objectifiable

personality disorder which, according to the DSM, does not have to be permanent and which had been in remission for 10 years. The possibility that there was a connection with the medication was always blindly brushed aside because it could not be proven by me. It didn't matter if I then came up with 6 research articles about the withdrawal syndrome and how it is often misinterpreted. I was a patient in the mental health system and apparently I lost my voice with that….

I never wanted to fight. For me it was important to learn from my case, not to damage psychiatrists. But if no one wants to listen, you easily lapse into fighting anyway. How else do you make yourself visible?

In 2020, Charlotte Bouwman held a sit-down event at the Ministry of Health. I too once thought, let me sit there. But I couldn't do it in my state. I would be yanked from the Binnenhof like an overexcited crying heap of human beings.

I feel so disempowered. I have approached journalists for years, but somehow my story is not allowed to be told, it seems. That is why I am grateful that you are writing it up for Mad in the Netherlands. I really don't want to vilify psychiatrists. I am well aware that my side of the story is only one side and that there are other sides as well. I do understand that. But since I have been ill, I feel like garbage. That does not apply to the people around me. They all stand beside me. They take my word for it. They just see how unbearable my life has become. But the doctors are all allowed to leave me to my fate, it seems. The very people who should have been able and willing to help me didn't seem to care. At least it felt that way to me anyway.

What I find so terribly troublesome is that almost every doctor who did tell me that the damage was plausibly due to the pills did not write it down in my file so that the battle started all over again with the next person. For example, a specialist once told me that it was logical that I had symptoms because the medication was a kind of sedative filter, which suddenly taken away could cause overstimulation of the nervous system. That really felt like recognition. Unfortunately, that specialist didn't write anything about it in my file so that the next time I visited another doctor, I had to start the battle that it was medication damage all over again.

I don't understand why people could have treated me this way....

Monique: I understand your sadness. It seems that doctors are sometimes reluctant to admit the alleged error because of their liability and insurance policies. The policy terms seem to require them to refrain from any promise, statement, or action from which the admission of liability may be inferred or the interests of the insurer may be damaged by it. However, according to the medical treatment agreement, the doctor also has a duty of disclosure. Your doctors may have shared something different verbally than on paper for this reason.

Anniek: But then a circular problem arises, doesn't it? If simply asking for help in suffering is not heard because people then think that the need is not there yet, then you automatically start screaming for help, to make the importance clear. But that can quickly be labeled as psychological, which makes you angry and sue to be heard. But in doing so, you then force your counselor into a defensive role opposite rather than beside you. And while I long for recognition, the doctor is busy satisfying his policy conditions. It is no longer about me. So what response is still okay then? How can I be heard?

Monique: My solution was to completely distance myself from medications and doctors, not to use my energy to fight for justice and recognition but to do all the self-care myself and recognize and do justice for myself. That did make me terribly lonely, though. And is that a realistic option to ask of those who are deathly ill? For financial, logistical, cognitive, social, corporeal, or whatever reason, it is not at all possible for everyone. Moreover, it really says everywhere that you have to approach a prescriber. My wish is for every prescriber to pursue experiential knowledge around PAWS.

Tapering is so individual that it is impossible to rely on guidelines, especially where antipsychotics are concerned because they act on a variety of neurotransmitters (and other forms of communication between brain cells), each with its own side-effect profile. Moreover, while they are intended to affect the brain, they also affect receptors throughout the body. Second-generation antipsychotics can thus cause a dizzying array of physical, emotional, and cognitive problems.

Ultimately, the solution cannot possibly be for all involved to fight each other and stay on our own little island for fear of each other.

Anniek: I did find it typical that especially the paramedics (physical therapy, dietician) listened much easier and accepted what I said. They obviously run less risk. I do understand that it's not easy to have to meet so many conditions, but the human aspect should be preserved. If through this interview more understanding comes from the profession, it would give my suffering … my impending death some peace, some sense. Still.

I find that I have some work to do over the next month before I can resign.

Monique: Rest, I grant you that wholeheartedly, but isn't that a bit much to ask? I can't, and I'm honest about that, I can't find peace in losing you. Nor can I, because then I would stop fighting for my own recovery. But I do respect your choice, I do. I know what unbearable suffering feels like, but is there really no way that I, or more importantly the community, can still help you?

Anniek: My life is a combination of over-stimulation and under-stimulation at the same time. The over-stimulation for sound and light makes me experience nothing so I can hardly experience happiness anymore. That also makes it difficult. I haven't had an easy life, but I really had my life in order with work, education, fun contacts and pursuits before I tapered off. And now I lie on my bed thinking of ideas of what I can do. And then I get excited and get up on which I immediately get "floored". I did complete some small things, but it took a lot of time and tears because I felt mostly how I could not accomplish what I wanted. We moved to Groningen at the time because surrounded by the noise in Utrecht, I broke down even more than here. Only here we could afford a detached house. This is not an ideal place, but that place doesn't exist either. We have searched in vain for about 3 years for solutions, also asking and receiving help from relatives. Within the Netherlands it is too busy in terms of people and noise, outside the Netherlands both my safety net and my benefits are gone. Everywhere I go or came there is too much noise for me. There was always something, both inside and outside. No matter how remote, 10 times out of 10 it goes wrong when I venture outside. There is no progress while I love being outside so terribly.

Monique: Do you think euthanasia is a once-in-a-lifetime opportunity? That it is now or never?

Anniek: No, but I also don't think it gets easier for me when I procrastinate. I allow myself rest despite the guilt I feel toward the people I leave behind. Euthanasia is sincerely the hardest thing I have ever done. I had to trust doctors to do it again. Also being conscious of euthanasia, regarding the grief of the people I leave behind, I find that so terribly hard. Also, because I actually want my life back most of all. I actually want to be able to live. Therefore, it's actually much easier to die impulsively. But I feel sorry for my loved ones, I can't do that to them. And besides, I would still die officially as a psychiatric patient who has committed suicide and I wouldn't be able to stomach that either…

Monique: When you explain it that way, I do understand you in your choice even more. Is there anything else you want to say in conclusion?

Anniek: I am extremely happy that my loved ones believed me immediately when I became ill. They found the contrast so great with how I was and how I became after the pill discontinuation, that they did not doubt my story. I knew my husband, family and many friends were thus supportive and comforting. New people also came my way who were struggling with ongoing withdrawal symptoms. Together we sometimes found the necessary recognition that was often lacking from professionals.

I liked that there were people who looked hard for solutions and people who helped make my voice heard. Even where it didn't bring what I hoped for. Without them, it would have all been worse….

On February 16, 2024, one of my rehab buddies died, due to ongoing suffering, by euthanasia. She went because she could no longer live with the daily torture the ongoing withdrawal of psychopharmaceuticals had caused her. I lived through the interview in addition to saying goodbye to her, my own goodbye to the terrible loneliness of an unknown and unrecognized illness. I hoped one day that I could make a difference for Anniek. In the end I understood that I had already made the biggest difference for her when I simply believed her in what she said, I acknowledged her in her suffering and continued to stand beside her as far as I

could. I hope that the people who are responsible for prescribing psychopharmaceuticals and deciding on reimbursing smaller doses so that suffering can be prevented will take up their role.

This article was co-sponsored by Pauline Dinkelberg and the Association of Discontinuing Medication.

This patient association represents the interests of people who want to responsibly reduce or completely stop their medication dosage. They are working hard to raise awareness of responsible medication taper and to get taper medication reimbursed under the basic health insurance package.

The article was translated by Carol Vlugt of the Association of Opioid Withdrawal. This association informs, supports and raises awareness about tapering off opiates as safely as possible.

Cover photo by Anniek Lemmens: Infinity

Let me go, in love
To where it is silent, stilled
I can be free again
In space without pain

Without sound

Let me go
Leave my love with you
Become one with nature
Her life our joy
Her storms our voice

If you can,
Live a little extra for me

Feast your eyes, feast
your ears
Care for the fragile
Smile for two
Take me everywhere with you

Live well, lovers

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